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Transition from Children's to Adult Services for Young People with Life-limiting Conditions: Findings from a Questionnaire Survey in Northern Ireland

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Abstract category: Palliative care in specific groups

Title:

Transition from children's to adult services for young people with life-limiting conditions: findings from a questionnaire survey in Northern Ireland.

Research aims:

To describe service provision for the transition from children's to adult services for young people with life-limiting conditions in Northern Ireland, and to identify organisational factors that promote or inhibit effective transition.

Study population:

Health, social, educational and charitable organisations providing transition services to young people with life-limiting conditions in Northern Ireland.

Study design and methods:

A questionnaire has been developed by the research team drawing on examples from the literature and the advice of an expert advisory group. The questionnaire was piloted with clinicians, academics and researchers in June 2013. The questionnaire focuses on components of practice which may promote continuity in the transition from child to adult care for young people with a life-limiting condition. The survey will be distributed throughout Northern Ireland to an estimated 75 organisations, following the Dillman total design survey method. Numerical data will be analysed using PASW Statistical software to generate descriptive statistics along with a thematic analysis of data generated by open-ended questions.

Results and interpretations:

The survey will provide a description of services, transition policies, approaches to managing transition, categories of service users, the ages at which transition starts and completes, experiences with minority ethnic groups, the input of service users to the process, organisational factors promoting or hindering effective transition, links between services, and service providers' recommendations for improvements in services. The outcomes will be an overview of the transition services currently provided in Northern Ireland identifying models of good practice and the key factors influencing the quality, safety and continuity of care. Survey results are due early in 2014.